Cynulliad Cenedlaethol Cymru | National Assembly for Wales
Datblygu Bil Aelod | Development of Member Bill
Y Bil Awtistiaeth (Cymru) - Datblygu'r Bil | The Autism (Wales) Bill - Bill Development
DMB(5) AWB09
Ymateb gan Di enw | Evidence from Anonymous

As a parent of a (Now 22yr old) Autistic son, I would like to impart some experiences and issues we as parents were faced with in ensuring assessments/report/treatment and placings were obtain and views on their effectiveness, which I hope can further understanding with the Assembly regarding the many issues we as parents and our son faced in coping with and managing this condition.

I will start day one so to speak where my son was diagnosed by myself initially at age 12 months, where I noticed certain traits he was exhibiting seemed allied to Autism via a TV program I had watched. Initially as we are disabled parents ourselves, there was disbelief by the medical profession that his behavioural and communication issue was down to Autism, indeed the GP at that time wrote that he believed communication issues were down to his parents disability (Deafness and Loss with both), and poor tuition of life skills. It was a very distressing time for us at that point. We were being 'blamed' because our son had Autism.

However we persisted and managed to get an assessment done at [redacted],where his diagnosis confirmed in 15 minutes that what we as parents suggested, were right in defining my son's issue, he was indeed Autistic (Aspergers Syndrome). While this vindicated us, there was no further support offered at that time. I managed as the male parent to get my son into a mum and tots nursery at 18 months of age, this was a great help to us, as the LA/SS had still not offered any support, citing a lack of personnel to manage it. However, 7 months after getting support from the local Nursery, the SS inspector who checked on such establishments saw my son there and said he would close down the Nursery unless my son was removed immediately, because he was too young to be there, and the Nursery sadly asked us to leave because of that.

I contacted the LA regarding support for my son, and eventually he was offered a placing at a SS-run nursery some miles away, it was conditional on me going every time with him, which I was more than happy to do. Again the reason given was that my LA had no staff or nurseries trained with children with Autism. When I went there with my son, it was to my view unsuitable, because it was a SS Nursery for children with parents who had issues e.g. took drugs, were alcoholics, disabled, or had other problems. I had to support him there until he was old enough to start pre-education.

When he started he still had huge issues of toilet and communications despite our full-time tuition to teach him, it was barely successful because he developed phobias of water/toilet etc. Indeed would soil himself in school rather than ask for the toilet.

The school later suggested he move to their special needs class, but again admitted they had no-one with experience of autistic children, and said the LA were not offering the school support either.

We decided to move home to be nearer what we thought were better access provision but he attended 3 different schools before age 11 with little or no support, until one special needs teacher who had informed us their school could not support my son, informed me that there were in fact special schools he could have gone to at age 6.

At age 11 the LEA again suggested he continue in mainstream education via an annex to senior school at [redacted]. AT that point I refused outright to allow that, my son had already lost his formative years support,and I was not prepared to allow that to continue and was angry my LEA and SS Dept had not informed me of the options or supported him up to age 11. I got on a train and went to [redacted] School in [redacted] as soon as I was aware of that school, and it was with their input, we forced [redacted] LA to place him there from age 11 onwards. Such was the problems with [redacted] LA/SS it was recommended they attend the very minimum or reviews and visits because they were viewed too negative to my son's progress and relationships between parents and LA had zeroed.

From age 11 to 16 my son improved by leaps and bounds at [redacted] College, [redacted]. During the final year there I was pushing for further educational support hoping to keep him within the specialised areas to continue the good works Ashgrove had given us and our son. I managed to get the welsh office to support a semi-residential option at the [redacted] college in [redacted]. Unfortunately the last day [redacted] LA/SS said he could not start because they needed a new assessment to take place first. My son had a breakdown, we had spent a year priming him for the change. [redacted] then suggested he go temporary residential in a care home, so they could assess him away from his parents and., give us a break.

We reluctantly agreed, but when the 6 weeks were up, the LA then refused to let him go to the college or, to return home. They claimed he had improved dramatically and now did not need the specialisation of the [redacted]college or support. This obviously led to legal proceedings because we objected to being misled and angry they had used the argument of improvement when he had another breakdown after they removed medication against our wishes, it was near fatal for my son and for me. In fact they LA were not paying for [redacted] it came from a Welsh office grant. [redacted] dug in and then refused to ferry him to the college saying they weren't liable. They backed down to my protests but only allowed my son day education not residential because that would have removed him from their original placing. Effectively to oppose us, they hoped by refusing to ferry him to college, that option would not now take place, but, the college ensured transport instead. [redacted] had initially insisted I pay £500 a week up front if I wanted my son to take up the college option!

As parents we were upset on seeing that the LA residential placing he was given although accessible to us to visit our son, was completely unsuitable for my son, and I managed to reverse the court/LA support for it, to get my son placed in Torfaen a far better and all autistic supportive option. We are still at odds with the LA, who apparently were not happy we as parents had overturned not only their choices of support, their advisors, but the court ones too.

In all this the primary issues were:

- Refusing to accept the diagnosis of Autism initially.
- Failing to support the parents or the child with the support when it was defined by consultants, either in education, or extra curricular.
- They offered neither my son nor us support.
- Had no social workers with any experiences of Autism.
- Decisions were being made by Newport LA auditors who did not refer to professional reports of need or even own SS depts.

Parents are wholesale unsupported, the legal aspects left parents in the dark and unsupported too. Ideally I would as a parent have preferred the LA NOT have complete autonomy over care provision for autistics, it is clear they're ignoring need, for cost savings. As regards to need definition, various agencies concerned with my son did not have an effective co-operative set up and were all competing against each other to save costs.

The LA was and is still ignoring parental suggestions or advice and overruling medical opinions at times also. Need definition and subsequent support, should be under a panel of people concerned with equal voice, to include medical agencies and educational, also post educational options.

It should NOT be down exclusively to LA to say what happens to a child who has autism but there should be acceptance of the consensus of all parties. Especially as no Social worker involved with my son (And he was provided with at least 7 in the past who had no experience indeed 3 or 4 my son or us even met), had any experience at all with Autism, they still don't. We require Social workers who understand what Autism is. Mainly because they are unable to understand reports given to them by professionals who ARE experienced. In one aspect I was told to e-mail a LA Auditor instead to ascertain why an option wasn't pursued.

Such parties should also include the actual CARERS be they the parent, or, paid carer or the home/residential providers, who at the 'coal face', so are best placed to define what the need is, as LA/SS are virtually writing off autistics in care. They were not checking on the support effectiveness either in residential homes, homes had to rely on advice from school, then had not the trained staff to implement the suggestions. It was the parents checks who forced the relocation. We have seen in real time, carers with our son suggesting various improvement options only for the LA too say no outright.

Many parents are being ill, Or even not informed of what transpires between officials including reports, whether good or not. Personally I myself had to coordinate the various agencies, and the LA never invited most to attend reviews. This disables the parent from being able to lobby for those improvements or to monitor progress, to display to the LA consensus of real opinion, because the LA won't tell them of what's takes place.   The Social worker did nor understand the terminology or what was suggested by ways of meeting that need by default.

LA's are leaning on care provision to deter parents knowing what transpires. In effect holding care provision to ransom to ensure 'control'.

That 'control' was not to ensure standards, but to cut provision and costs, the less we knew about, the less they would need to provide. There were heated rows between [redacted] School and the [redacted] LA. Ashgrove itself provided all the back up for my son and indeed for us too,all the time he was there.. Including teachers attending our home and taking him on trips etc where they footed the cost to give is a break.. [redacted] demanded £22 an hour to do the same.

I've attended various 'reviews' and indeed court proceedings, where the teachers, colleges, schools and residential carers were not allowed to attend to give a view. Entire interpretation of needs and progress is kept within the LA itself to decide if valid or not, this is a system of secrecy that is detrimental to support Autstics, and fragments a proper assessment to the point it is hit and miss,indeed the [redacted] initial assessment that led to him entering residential care was flawed and led to me being able to get my son an extra years support in a college. The question of LA illegality and misinterpretation, seems real to me, but we lack legal advice or means to counter.

In one court proceeding they accused my son's college of being an 'open prison', and, his teachers 'amateur and untrained', yet the welsh assembly had approved of this college option, it is the leading and only dedicated autistic college in S Wales, the LA itself had approved the college. [redacted] LA has used the exclusion of valid parties, to support their own cost cutting agendas and to mislead the court in my view. They used all sorts of bullying means via 'best interest of the child' etc,but were acting AGAINST those interests and were simply covering up huge mistakes. The reality the parents overruled all their major decisions since has not made for much co-operation either. It's a perpetual stand off, which is certainly NOT in anyone's best interests.

I would change the law to include clauses to to ensure ALL parties concerned in the care of our autistic children are at all meetings and all legal options too. Reviews were professional input is paramount should include the professionals making those reports, Newport does not invite parents to those reviews.. Given SS do not understand what they are reading, ignoring the view of pros and parents who do, is ridiculous. There is no doubt the LA could have prevented my son receiving his rightful support had not his parents been so determined to get them, the LA wanted input inadmissible from the very carers providing my son's 24/7 support who were best placed to know what that was, this was to prevent parents asking relevant questions,it is patronising too, in that they feel parents won't understand their own child's condition..

I would also ask the right to transfer LA authority autonomy financial and other, to other areas who are doing better at meeting autistic need. e.g. as my son is no longer a [redacted] resident, a registered [redacted] voter, his medicinal, educational, and future care support is there too, then logic suggests the Autonomy should be there as well. Successions of uninformed Social Workers with no training just makes issues for everyone else. If you have to have brain surgery you don't hire a florist to do the operation.

I hope this helps form a clearer view of what parents are facing from abysmal LA/SS diktats based not on need at all, who also as a result subject both child and parents to unimaginable stresses and insecurities. SS must be trained in the area they are working in, it is clear they lack enough knowledge to understand enough to do their job. It requires specialisation.